



# NETWORK NEWS

## News from the Utah Birth Defect Network

January 2004

Volume 1, Issue 1

<http://health.utah.gov/birthdefect>

### Notes from the UBDN Director

Birth defects occur in about four of every 100 live births, with only 35 percent having a known cause. Preventing birth defects is a relatively new phenomenon with the greatest impact, thus far, being the use of folic acid *before* and during the first three months of pregnancy for neural tube defect prevention. Nonetheless, this discovery provides hope that other "folic acids" exist and more birth defects are preventable.

Timely and accurate information about birth defects is necessary to drive efforts toward primary prevention, as well as secondary disabilities prevention. To evaluate public health intervention strategies, statewide birth defect surveillance systems must be in place. Birth defect surveillance systems provide important data that enables a state to determine geographic distribution, describe maternal characteristics, and identify trends over time.

The Utah Birth Defect Network (UBDN), created in 1994, is a public

health surveillance system that monitors the occurrence of all major structural malformations in the state. The UBDN is housed within the Bureau of Children with Special Health Care Needs, Division of Community and Family Health Services, at the Utah Department of Health. The UBDN began only monitoring neural tube defects in 1994. This pilot project was very successful and other defects were added to the UBDN list in 1995 and again in 1997.

With additional funding, the UBDN expanded to a full surveillance system in 1999, monitoring the occurrence of all major birth defects, with few exceptions. Not only is it important to prevent birth defects from occurring, but it is as important when a child is born with a birth defect to minimize the physical, social and developmental problems that may occur as a result of the primary birth defect. To this end, the UBDN is committed to its mission to:

*Assess the impact of congenital malformations upon infants, families, and*

*health care in Utah, determine factors involved in etiologies that provide insight into primary prevention strategies, and assist families and their providers in secondary disabilities prevention.*

As of 1999, hospitals and laboratories must to report any identified birth defect in children up to two years of age, Administrative Rule (R398-5). This Rule is part of the Utah Department of Health, Health Code Statute regulating public health issues.

The UBDN has received funding from the Centers for Disease Control and Prevention since 1995 that has allowed for and supported the growth of the UBDN surveillance project. The Utah Chapter of the March of Dimes provided some funds in 1995 and 1996. Ongoing funding is now being sought in order to continue the surveillance efforts of the UBDN. Marcia Feldkamp P.A., MSPH  
UBDN Director

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Utah  
Department  
of Health

# A Historical Perspective on the UBDN

Speaking for the pediatrics and genetics communities of the great state of Utah, I am particularly pleased to have witnessed the growth and development of the Utah Birth Defect Network (UBDN) over the last decade. This undertaking, while supported in spirit and in dollar by the Utah Chapter of the March of Dimes, the Centers for Disease Control and Prevention, and the Utah Department of Health (UDOH), has been competently created and led by Marcia Feldkamp.

Marcia, a person of many talents, possesses above all other a vision

and knack for old fashioned hard work. This vision and diligence, in combination with her leadership, laid the foundation for the existing "well oiled" structure that we now call the Utah Birth Defect Network. But it was not always this way. Ten years ago, with the blessing of the Pregnancy Risk Line and the UDOH, Marcia had to face the commonly occurring skepticism. Many asked, "Is this just head counting?". And the answer is obvious: we should and need to provide this surveillance.

This registry is the first step to finding causes of birth defects and

to planning statewide management of services. Now, we look forward to the collaboration of the UBDN with the genetic scientists at the University of Utah and, eventually, a clearer understanding of the causes of birth defects. Knowing causes leads to prevention and, ideally, more successes like the folic acid story! Currently, we know that neural tube defects are decreasing in Utah, however, for unknown reasons, Utah also has the highest rate of cleft lip and palate in the nation.

John C. Carey, M.D., M.P.H.  
Pediatric Geneticist

## UBDN Surveillance Staff

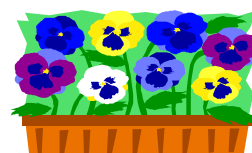
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## Thank YOU!

I would like to thank all of the Health Information directors and staff members; privacy/compliance officers; Women's Services Center managers and staff; and champions in hospitals across the state with whom we met over the summer to discuss the UBDN! We welcome your interest in our public health surveillance activities. Your as-

sistance in planning how best to work with you, given the new constraints since the Health Insurance Portability and Accountability Act (HIPAA) of 1996 took effect in April of this year. These visits have been extremely valuable from our perspective, as we hope they have been for you. We look forward to a continuing partnership with

you and your health care facilities. Lynne MacLeod, M.Stat., Surveillance Coordinator.



A bouquet to say thank you!

# Utah Center for Birth Defects Research and Prevention

The Utah Birth Defect Network (UBDN) was recently awarded a grant to become one of ten states participating in the National Birth Defects Prevention Study (NBDPS). The NBDPS, which is funded by the Centers for Disease Control and Prevention (CDC) in Atlanta, is the largest study ever conducted to uncover the causes of birth defects.

Beginning in late 2003, the UBDN will be conducting telephone interviews with women who had pregnancies affected by a birth defect, as well as women who gave birth to babies without a birth defect. These interviews will provide researchers with

**"We hope to discover risk factors that contribute to birth defects as well as protective factors that lower the chances of birth defects."**

critical information about factors in the environment that may be related to birth defects. Cheek cell samples will

also be collected from mothers, father, and infants to study how genes and the environment interact.

The Utah study looks at a large group of women, so its findings will apply to "the average woman" rather than to any specific individual. We hope to discover risk factors that contribute to birth defects, as

well as protective factors that may lower the chances of birth defects. Findings from the study will be published in medical journals, and they may also be covered in the news. For more informa-

tion about the NBDPS, please contact Jennifer Herrick at [jherrick@utah.gov](mailto:jherrick@utah.gov).

Rasmussen, S. A., E. J. Lammer, et al. (2002). "Integration of DNA sample collection into a multi-site birth defects case-control study." *Teratology* 66(4): 177-84.

Rasmussen, S. A., R. S. Olney, et al. (2003). "Guidelines for Case Classification for the National Birth Defects Prevention Study." 27.

Yoon, P. W., S. A. Rasmussen, et al. (2001). "The National Birth Defects Prevention Study." *Public Health Rep* 116 Suppl 1: 32-40.

## Local and National Resource Information on Birth Defects

The **March of Dimes Birth Defects Foundation** is a national agency dedicated to preventing birth defects, low birth weight, and infant death. Its website link, "health library," and "resource center" have a wealth of information. You can get a free copy of "Mama—Your Guide to a Healthy Pregnancy." Toll-free number: 1-888-663-4637  
Internet: [www.modimes.org](http://www.modimes.org) (National)  
[www.modimes.utah.org](http://www.modimes.utah.org) (Utah Chapter)

The **Centers for Disease Control and Prevention's (CDC) Division of Birth Defects, Child Development, and Disability and Health** website provides information on CDC's activities targeting birth defects and childhood disabilities. Toll-free number: 1-888-232-6789  
Internet: [www.cdc.gov/ncch/cddh](http://www.cdc.gov/ncch/cddh)

The **National Birth Defect Prevention Network** website provides information on state birth defect monitoring programs, and national, and international links. The NBDPN is a nonprofit organization of individuals throughout the country who are involved in birth defect surveillance and research.  
Internet: [www.nbdpn.org](http://www.nbdpn.org)

The **Utah Birth Defect Network** has Utah specific information and many local and national links on birth defects. Toll-Free number: 1-866-818-7096  
Internet: <http://health.utah.gov/birthdefect/>

The **Utah Chapter of March of Dimes** is a national agency dedicated to preventing birth defects, low birth weight, and infant death.

Internet: [www.modimes.utah.org](http://www.modimes.utah.org)  
The **Share** pregnancy and infant loss support group.  
Toll-free number: 1-800-821-6819  
Local number: 1-801-272-5355

The **Compassionate Friends** program assist families with grief in a positive way following the death of a child of any age, and provide information to help others be supportive.

Utah number: 1-801-561-9862  
Toll-free number: 1-877-969-0010  
Internet: [www.compassionatefriends.org](http://www.compassionatefriends.org)

The **Cleft Palate Foundation** site has a wealth of information for parents of babies with cleft lip and cleft palate. Toll-free number: 1-800-24-CLEFT  
Internet: [www.cleft.com/cpf/cpffrm.html](http://www.cleft.com/cpf/cpffrm.html)  
**Spina Bifida Association of America**



works to prevent spina bifida and improves the lives of all affected. This site has a lot of general information about spina bifida.

Toll-free number: 1-800-621-3141  
Internet: [www.sbaa.org](http://www.sbaa.org)

The **Alliance of Genetic Support Groups** helps individuals and families affected by genetic disorders. The site has a search directory by genetic condition, organization name, and available services.

Toll-free number: 1-800-335-GENE  
Internet: [www.geneticalliance.org](http://www.geneticalliance.org)

The **National Information Center for Children and Youth with Disabilities** provides information and referral on disabilities and related issues. Toll-free number: 1-800-695-0285  
Internet: <http://www.kidsource.com/NICHCY/index.html>

SAVE THIS DATE

Utah Birth Defect Network  
PO Box 144697-4697  
Salt Lake City, Utah 84114-4697

Place Label Here

STAMP

National Birth Defect  
Prevention Network  
7th Annual Meeting  
Marriott City Center  
Salt Lake City, UT  
January 21-23, 2004



For more information contact:



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Or visit our website at:

<http://health.utah.gov/birthdefect>

**For agenda and  
registration  
information please**

**visit:** [http://www.nbdpn.org/NBDPN/](http://www.nbdpn.org/NBDPN/annualmeeting/2004/index.html)

[annualmeeting/2004/index.html](http://www.nbdpn.org/NBDPN/annualmeeting/2004/index.html)

Registration Fees:

3-day- \$150.00

1-day- \$50.00